



Nia

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IS INDESCRIBABLE."



NIA'S STORY

Nia was born with a very rare genetic skeletal dysplasia known as Ellis-Van Creveld (EVC) syndrome. She came to Nemours when she was 2 months old to receive specialized Neonatal Intensive Care Unit (NICU) care for children with dwarfism, and especially EVC. She and her parents, Erica and Antoine, were no strangers to NICU life, having spent weeks in the NICU at her delivery hospital. By the time they left Nemours, Nia and her parents had spent almost four months in a NICU.

Erica describes her NICU journey as *"a blessing - yet unfathomable, unrelenting, traumatic, joyful, dreadful, overwhelming, awful (at times) and a roller-coaster ride full of ups and downs."* Although the days were trying, Nia and her family quickly bonded with her care team. They even celebrated the holiday season together.

Erica recalls, *"The love we feel walking through the doors at Nemours is indescribable. We are always met with love, care and compassion like I've never seen before. There is a vested interest and a sense of empowerment given to us as parents to be in control of our child's care."*

Nia is a miracle and a warrior. She fought so hard to be here, and her family is dedicated to helping other families going through similar experiences.

Help us give every baby like Nia a healthy chance. [Donate Today!](#)

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